

AMENDED IN ASSEMBLY JULY 2, 2003

AMENDED IN SENATE APRIL 29, 2003

AMENDED IN SENATE APRIL 9, 2003

SENATE BILL

No. 231

Introduced by Senator Murray

February 14, 2003

An act to add Section 124982 to the Health and Safety Code, relating to hereditary disorders.

LEGISLATIVE COUNSEL'S DIGEST

SB 231, as amended, Murray. Hereditary disorders: Newborn Screening Advisory Committee.

The Hereditary Disorders Act requires, among other things, the Director of Health Services to establish any regulations and standards for hereditary disorders programs that the director deems necessary to promote and protect the public health and safety.

This bill would require the director to appoint a Newborn Screening Advisory Committee with members who meet specified qualifications.

This bill would require the committee to meet at least annually to review newborn screening programs and to report annually to the Legislature and the Governor on or before October 30 on specified topics.

This bill would authorize the ~~committee~~ *department* to apply for and receive federal and private funding to fund ~~its~~ *the committee's* activities. This bill would provide that the committee shall operate exclusively from these funds, and shall only operate to the extent these funds are available.

Vote: majority. Appropriation: no. Fiscal committee: yes.
State-mandated local program: no.

The people of the State of California do enact as follows:

1 SECTION 1. Section 124982 is added to the Health and
2 Safety Code, to read:
3 124982. (a) The director shall appoint a Newborn Screening
4 Advisory Committee and establish rotating terms of service for the
5 committee members.
6 (b) The committee shall consist of one or more individuals
7 affected by a genetic disorder or parents of individuals affected by
8 a genetic disorder; advocates for women and childbirth issues;
9 health care providers specializing in clinical genetics, pediatrics,
10 obstetrics, molecular biology, cytogenetics, *bioethics* and
11 biochemical genetics; representatives of hospital administration,
12 the insurance industry, the biotechnology industry, and genetic
13 counseling; and professional organizations representing
14 physicians and registered nurses.
15 (c) The committee shall meet at least annually and shall review
16 newborn screening programs conducted under the Hereditary
17 Disorders Act, and report to the Legislature and the Governor
18 annually on or before October 30 with respect to all of the
19 following:
20 (1) The availability and utilization of newborn screening.
21 (2) The quality of services provided.
22 (3) The cost and funding of services.
23 (4) The need to discontinue or add additional services or
24 improve the quality, quantity, *or* distribution of services, or
25 provider reimbursement.
26 (d) Committee staff shall include at least one full-time position.
27 (e) The ~~committee~~ *department* may apply for and accept
28 federal funds for the purpose of funding the activities of the
29 committee. In addition, the ~~committee~~ *department* may accept
30 gifts and donations from any source, including individuals,
31 philanthropic foundations or organizations, corporations, or
32 corporate endowments *that meet the requirements of subdivision*
33 *(f)*. The acceptance and use of federal funds, ~~gifts, or donations or~~
34 *private funds* may not entail any commitment or pledge of state
35 funds, nor obligate the department to continue the programs or

1 activities for which the federal *or private* funds are made available.
2 The committee shall operate exclusively from private and federal
3 funding and shall only operate to the extent these funds are
4 available.

5 (f) (1) *Funding for the committee shall not be provided by any*
6 *person or business entity that is involved in providing products or*
7 *services associated with newborn screening if it is reasonably*
8 *foreseeable that a change in state policy regarding newborn*
9 *screening would have a material financial effect, distinguishable*
10 *from its effect on the public generally, on the person or entity.*

11 (2) *For purposes of this subdivision, the following definitions*
12 *apply:*

13 (A) *“Business entity” includes a director, officer, partner,*
14 *trustee, employee, manager, or consultant of the business entity.*

15 (B) *“Person” includes an individual, or a member of his or her*
16 *immediate family.*

